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A MODERN PLAN FOR MODERN SERVICES TO THE MENTALLY RETARDED



*U.S. Department of
Health, Education, and Welfare
Social and Rehabilitation Service
Rehabilitation Services Administration*

"This report is predicated upon the strong conviction that the mentally retarded person should be served with as little dislocation from his normal environment as is consistent with the special character of his needs. Those needs should be met as close to his home as possible and in such a way as to maintain his relation with his family and peers."

—Report to the President, A Proposed Program for National Action to Combat Mental Retardation, 1962

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*Robert I. Jaslow, M.D.
Director
Division of Mental Retardation*

*U.S. Department of
Health, Education, and Welfare
Social and Rehabilitation Service
Division of Mental Retardation
Arlington, Va. 22203*

“THE 6-POINT PROGRAM”

Community
Coordination
of
Services

Efficiency

An MR Specialist
in Each
Generic Agency

Standards for
Services and
Training Offered

Role Definition and
Criteria for Utilization
of Specialized Services,
Agencies, and Facilities

Community
Generic
Agencies

Quantity

Basic Training
in MR for Every
Personal Services
Worker

A Modern Plan for Modern Services to the Mentally Retarded

INTRODUCTION

For the past 3 years, the Division of Mental Retardation and its predecessor programs have been seeking to help in the building of services which will truly meet the needs of America's 6 million retarded citizens. To recite the history of those 3 years here would be beside the point. Suffice it to say that they have been active—and educational.

We have, in the nature of things, put great emphasis on planning and coordination of programs at State and local levels. And out of this emphasis have come most of the lessons we have learned.

We have discovered, for example, that what we have known to exist—a severe shortage of trained manpower—not only exists, but threatens to get worse before it gets better.

We have found ourselves in a difficult competitive position for our full share of the community resources.

We have not found a solution to the problem of provision of services. The generalist's approach which is comprehensive still vies for our attention with the specialist's higher quality but more fragmented approach.

We have learned that development of services for the retarded must proceed in keeping with the general development of all personal services in the community and yet must maintain the identity of the mentally retarded.

Summing up our lessons learned, and perhaps most important of all, we have discovered that means must be found to extend services to all the retarded with those resources which are available.

The lessons I have outlined underscore the fact that we cannot expect, simply by developing a number of programs for the mentally retarded in a community, that these shiny new programs will then automatically fit together into a dynamic structure. It is difficult enough for the community to plan concretely for all the needs of the retarded in the beginning. Precise data are lacking. There is little or no definition of function. Philosophies

change. And if planning for the present is difficult, planning for the future is nearly impossible. Yet it must be done. It has to be done in the full knowledge of the difficulties involved: The financial and manpower problems, the changing missions of programs and agencies, the lack of specific treatment and preventive programs, and the uncertain future in which the only certainty which exists is the certainty of change and the development of new trends.

Planning in a vacuum is no planning at all. We have to work with what we have. Attempts to develop mental retardation service programs in a vacuum can only result in isolated programs without community understanding, backing, or support.

It is with these factors in mind that we have devised a model 6-point program for the proper balance and coordination of community services.

POINT 1

OPEN EVERY GENERIC COMMUNITY AGENCY TO THE RETARDED INSOFAR AS THESE AGENCIES' COMPETENCE AND ABILITY PERMITS

A definition is in order here. By generic agency, I am referring to any health, welfare, educational, rehabilitative, or employment agency in the community whose purpose is not for the specific care of the mentally retarded. An example might be an orthopedic clinic not specifically for the mentally retarded, which would be considered a specialized service in other circumstances, but would be considered generic in our conceptual model. Our reasoning is that if we are to provide the quantity of care necessary, we have to consider the fact that most retardates do not require complex and specially trained assistance in every situation throughout their lives.

Most retardates fit into the mildly retarded grouping and can cope with most situations without help or, at least, without the help of specialized agencies. We should not be thinking so much of types of retardation. Rather, our attention must be directed to the situations which retardates are apt to encounter. Thus, a child may be mildly

retarded yet have complex genetic problems or learning difficulties while a far more seriously retarded individual may have such comparatively slight problems (or at least uncomplicated ones) as a toothache or a fractured leg. Actually most of the services the retardate needs are—or should be—available in the community.

Moreover, it takes time for the service worker to develop a rapport with the family of the retardate, learn its strengths and weaknesses, and know the community and its full range of services in order to determine the most practical treatment plan. These are factors which argue persuasively for local rather than distant care and for care given by agencies and professionals who already know this family.

Just as the individual cannot be split into separate parts for treatment, we are coming to the understanding that close inter relationships which bind the family together require that it be treated as a unit. Thus the development and mushrooming of specialized agencies which isolate the retarded individual from his family must be carried out only after careful consideration.

There is still another factor which inhibits the retardate from receiving the treatment he needs in the generic agency. Too often, the mentally retarded person is refused service because he is identified as a retardate. Furthermore, the presence of specialized agencies available for the retarded tends to encourage referral to them almost automatically. Thus begins to develop a mysterious aura of specialization supposedly required for this exotic and difficult condition. The retardate quickly moves beyond the scope of the generic agency regardless of his true need—a need which most often could be supplied in the very agency which shuts him out. This develops into the concept of mental retardation as an all-or-none condition rather than one with graduated problems.

Again arguing for the greater use of generic services is the logistical problem of distance. Local agencies are simply easier to get to. Why send the retardate miles from his home unnecessarily when by doing so we also send him away from the service which has been treating his family for years, which knows his family and its

problems, and which by all reasonable standards, should be best equipped to treat him?

Today the mental health field is moving towards family unit treatment and away from child guidance and adult mental health clinics. Social workers are moving again toward family unit treatment, and there are strong recommendations that medical schools should be developing a new specialty—the family specialist—to handle the majority of medical situations for the entire family and act as the family's fixed point of referral for its full complement of service. We who are interested in the retardate should be thinking in these same terms.

POINT 2

THE PROVISION OF BASIC TRAINING IN MENTAL RETARDATION FOR EVERY HEALTH WORKER

I would go further than that and say that every personal service worker should have such training. This would not be so vital for such technicians as the X-ray or laboratory worker, but is a must for every personal service worker who offers services in a health, welfare, educational, rehabilitative, or employment situation.

With such training, the generic agencies would be more easily persuaded to open their doors to the retarded. This would greatly facilitate the understanding needed for satisfactory case-finding, referral, and timely intervention.

This basic knowledge would not have to be very extensive. It should be enough to enable the worker to know the essential concepts of retardation along with the major problems and possible relationships. Thus he would be able to identify most retardates or at least to refer cases for proper identification, would be able to handle basic questions, and could be aware of the relationship of specific services to the problems of the individual retardate.

With the ability to make logical referral at the appropriate time, the health worker or other personal service worker will be able to avoid passing the retardate and his family around haphazardly

to inappropriate services, wasting usable professional time, and perhaps missing the optimal period when intervention of the right kind would do the most good.

POINT 3

THERE IS A NEED FOR ROLE DEFINITION AND CRITERIA FOR UTILIZATION OF SPECIALIZED SERVICES, AGENCIES, AND FACILITIES

This is another point which would broaden our quantity of services and manpower greatly, thereby permitting more retarded people to be served while not subverting the manpower and funds available to the community.

Although we must recognize the value of generic services and agencies, we do not propose an either-or situation in regard to generic vs. specialized services. Both are needed for a balanced program but must be properly fitted into the overall community services structure.

One of the major problems facing the field of planning for services to the retarded is the lack of definition of role of the various agencies. Unless this definition is made, it is most difficult to fit the various service roles together into the total spectrum of services which alone can guarantee the continuum of care the retarded require.

Needless to say, the confusion and loss of time for both professionals and patients created by this lack of definition is considerable—and far more than we can tolerate.

Another very important factor is poor utilization of the specialized agency or facility. Simpler cases are not usually appropriate for the specialized agency. When they are referred to it, two things happen. The agency receiving these cases is prevented by the very volume of need from performing its principal mission—provision of service to the more complex or difficult case, training, research, and demonstration of new techniques.

In addition, the generic agency which should be handling the simpler cases is prevented from doing so and, as a result, may not shoulder its responsibilities for handling even simpler levels

of care for the retarded. Thus we defeat the purposes which we are trying to propagate, and the results of evaluation of previous planning become distorted and meaningless. Thus even future planning for such important factors as manpower is made useless.

It is disturbingly true that at present, only a small percentage of our retarded population is being provided services which are truly comprehensive both in variety and in time. Yet we are committing tremendous sums of money and numbers of people to just such programs.

In order to justify the continued presence of these services, we must use them to a more efficient end than we are currently doing. That is why it is so pressingly important that we sort out the missions of various kinds of services and make certain that problems are referred to services where they can be handled as simply as possible.

What we have been talking about in the first three points relates primarily to quantity of services for the retarded and to those services directly working with the retarded. We need to be concerned about quality, and the next two points refer to this.

POINT 4

THE PLACEMENT OF A MENTAL RETARDATION SPECIALIST, EITHER FULL-TIME OR PARTTIME, IN EVERY GENERIC AGENCY OF ANY SIZE OR SIGNIFICANCE

This accomplishes several things. First of all, it provides better distribution of specially trained manpower, putting professionals in positions where they can best utilize their skills in behalf of the greater number of retardates, thus relating to another great problem today which is the inequality of levels of service in different areas throughout the Nation.

More than that, point 4 provides a backup service enhancing staff competency in the generic agency. The mental retardation specialist in the generic agency acts as a consultant and inservice

educator offering greater likelihood that the generic community service and health worker will accept the retarded patient. This, in turn, contributes to the quantity of services offered in the community, but it also can upgrade considerably the quality of those services. Furthermore, it satisfies another important problem concerned with the information explosion and the lag in the use of new knowledge.

It is obviously impossible for everyone to keep up with all the new developments today. We keep up with only those areas in which we have a special interest. The inclusion of the mental retardation specialist, either full or part time, in each sizable generic agency thus adds a professional with one special field of interest in which he keeps currently informed.

Since this specialist is trained in the multi-disciplinary approach, though not necessarily skilled in every specialty contributing to it, he would be expected to have some knowledge of new developments as they relate to the other disciplines. Thus he becomes the intake channel for new knowledge and new techniques keeping the quality of care at a high level, and reducing the lag time between new knowledge and the implementation of that knowledge.

POINT 5

WE MUST DEVELOP STANDARDS FOR SERVICES AND TRAINING

“Standards” can have a very specific meaning. We are talking more generally at this point. Here, I am using the word to include those standards established nationally by a variety of groups, and all those established for various reasons by State and local groups. In addition, authoritative statements, guidelines, and regulations should be considered. Those to be utilized are determined by the community when appropriate to control and justify the expenditure of tax dollars, to help in program evaluation, to stimulate program improvement, and to use in determination of the need for continuance or modification of various programs. Standards are a quality control factor for the good of the community, the family, and, most important, the patient.

This discussion has centered to date on quality and quantity of programs. We need to say a word for efficiency, for any discussion of a model for services of any kind is incomplete without consideration of this factor.

POINT 6

A COORDINATING MECHANISM WITHIN THE COMMUNITY IS A REQUISITE FOR BALANCED SERVICES AS WELL AS FOR MENTAL RETARDATION PLANNING

The coordinating mechanism should relate to the services existing in the community, and would probably be utilized best if based upon a service such as an information and referral center. Such a center would have the added advantage of offering a positive service to the generic or specialized agency. Thus it would be better able to enlist the cooperation and use of its coordinative role by existing agencies.

This would result in such needed side effects as an agreement on terminology, bringing improved communications, better data collection, and more unemotional and rational planning. The coordinating mechanism should be concerned with finding and eliminating those barriers which prevent the retarded from access to community services.

More than that, the center should serve in the coordination of inservice education and training and should be a meeting ground for planning across agency lines. This service might also be part of a community coordinating mechanism with a far wider role than merely mental retardation. If this is to be the case, however, the community agency should have an identifiable subsection responsible for retardation.

The coordinating body should be concerned, then, in bringing together all the fragments for the continuity of services needed by the retarded, assuring balance in the development and delivery of services, and making sure that the retarded get their fair share in both quantity and quality of the services available in the community.

CONCLUSION

This, then, is our 6-point model for a community service program. Individually, these points have been enunciated before. But that is not the point. The six points must be considered in a group in order to produce the various checks and balances necessary to the development of a balanced program.

Embodied in the whole model is the idea of economy—a very basic concept indeed—and vital since the amount of new knowledge available and still developing will stretch our resources to the bursting point. We have to recognize that in our field of mental retardation we cannot expect to obtain the ultimate in services when none of the other problem areas facing the community can do so. After all, we are not alone. Other conditions find the same lag between knowledge and implementation and have to compete for their fair share of the financial and manpower resources.

But under the system I have suggested, we have a fair fighting chance of obtaining our share of available community resources for the retarded. This fact plus the flexibility of the model enables us to bring the retardate together with his community's resources in an equitable, adequate manner.

We do not suggest—and for good reason—that these six points are unyielding and not to be adjusted. Quite the contrary. If a community needs to put more emphasis on specialized services and facilities, this can be done by lowering the criteria which determine their use. If the need is to channel more retardates into generic community agencies, we can always raise the criteria. The coordinating mechanism can and should be given a wide latitude in such areas as developing communications systems for the community. All this serves to give the community the basic control it needs to insure the best services compatible with the total availability of services.

There is one other important point which should be considered. We are here interested in the problem of mental retardation—one categorical problem which requires consideration in the total community framework. Nothing we

have said here, however, could not with modification be applied to other categorical problems. In this age of comprehensive care, all of us must be thinking in terms of service to these various categories. But we must be concerned that we do not swing full circle. We moved from generalized services to specialized services in order to improve the quality of care. We achieved this improvement, but we also developed a degree of fragmentation which is not so desirable. Now, in the attempt to avoid fragmentation, we must be careful not to go back to the lower quality which generalization might bring.

We must use the elements of both systems, providing comprehensive care without too much decrease in quality. The great movement we are seeing toward the neighborhood health center—the center which will eventually become in effect, if not in fact, a personal services center—brings us closer to the time when health, welfare, educational, rehabilitative, and other services will be recognized as closely intertwined and when services to the family unit in all these areas will be closely coordinated.

What we really are dealing with, it seems to me, is a system—or a model of a system—in which, already, communities are beginning to participate. Many communities today have one or more elements of the 6-point model I have discussed. As the complete models are put together in more and more communities, we will indeed be reaching the day when the retarded member of our society does in fact receive something approaching his fair share of the services he so desperately needs.

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